

The background features a series of concentric, overlapping circles in light gray and white, some solid and some dashed, creating a subtle, geometric pattern.

Role of Research Building Agency with People with Intellectual Disability

Morag Kelly

Introduction

- My name is Morag
- PhD student at the Sydney Centre for Healthy Societies – The University of Sydney
- I did a literature review on social science papers
- Focus: building agency and inclusion for people with intellectual disability

My experience

- My older sister Bridget has Down syndrome
- She is mostly non-verbal
- She was not supported in primary or high school
- This meant she was excluded from activities

A red speech bubble graphic with a white outline, containing the text 'My research today'. The bubble has a tail pointing downwards and to the right.

My research today

- Is about inclusion
- Showing how people with intellectual disability are currently included
- What methodologies are used to include people with intellectual disability

A large red speech bubble graphic with a white outline, pointing downwards. The text "Agency and Inclusion" is centered inside the bubble in white. The background features faint, overlapping concentric circles and curved lines in light gray and white.

Agency and Inclusion

What is Agency?

- Agency means people are able to make decisions about their own lives
- Means people feel included in their community
- Being included in talks about their lives means people have better chance of agency

Why is Agency Important to People with Intellectual Disability?

- People with intellectual disability have not had control over their own lives
- They were not given the same rights
- Non-verbal people with intellectual disability are still vulnerable
- ‘Substitute decision maker’: makes decisions for someone who cannot make them on their own (Carney, Bigby & Douglas 2018, 65).
- Substitute decision maker is usually a family member, friend or support person
- Supposed to make decisions based on what that person wants

What Does Agency Look Like for People With Intellectual Disability

- Supported decision making: people work together to make decisions
- Means people with intellectual disability can help make choices
- Opportunity for agency

Agency and Inclusion in Disability Research

- People with intellectual disability need to be able to participate in research that is about them
- Cannot talk about disability as one big experience
- People who are non-verbal are often excluded from research
- Research needs to be more accessible for people with intellectual disability

Methods

- I did a literature review
- I looked at papers about intellectual disability and inclusion
- Papers were written in last ten years
- How well did these papers include people with intellectual disability?

Data collection

- I searched:
 - ‘Intellectual Disability’ and ‘Agency’;
 - ‘Intellectual Disability’ and ‘Inclusion’;
 - ‘Intellectual Disability’ and ‘NDIS’; and
 - ‘Intellectual Disability’ and ‘Research’.
- “Agency”, “Empowerment”, “Inclusion”
- Used qualitative research
- Australian and international papers



Data analysis

1. Research aims

- Did they want to include people with intellectual disability?

2. Methodologies

- Which methodologies were most popular?

3. Success of research aim

- Did they include people with intellectual disability?

The Bridget Test

- Used to decide whether research genuinely tried to include people of different abilities
- Could Bridget share her thoughts with the accommodations given?
- Did the researcher assume the verbal abilities of participants?

Findings

- 12 papers
- Used qualitative methods
- Political, economic and social inclusion and inclusion in research
- Not all papers aimed to include people with intellectual disability
- If we are talking about the importance of inclusion then we have to start with our own qualitative research.

1. The Stated Desire

- Some expressed clear need for agency in research
- Others said they were not inclusive enough
- Perry, Waters and Buchanan (2019) – agency and NDIS
- Whitman (2017) used interviews but did not have non-verbal participants

2. The Problem with Substituted Decision Making

- Research using carers to answer on behalf of people with intellectual disability
- Agran, Root-Elledge, Moody, Ginn & Estrada-Reynolds (2020) – capacity of people with intellectual disability to vote
 - Only asked carers
 - Online survey
 - 7 demographic questions and 25 questions about the person they support
 - ‘Do you agree that people with intellectual disability cannot be expected to provide a meaningful vote?’ (Agran et. al. 2020, 6).

2. The Problem with Substituted Decision Making

- Would one of her support providers know Bridget's understanding of voting?
- Likely based off assumptions not conversations
- Skills and goals of people with intellectual disability are often underestimated
- Makes agency difficult to achieve

2. The Problem with Substituted Decision Making

- Tried to include people with intellectual disability but only used carers
- Lloyd, Moni, Cuskelly & Jobling (2021) – studied NDIS planning
 - Semi-structured interviews to gather experiences
 - Carers were comfortable with interviews but the participants with intellectual disability found it difficult

3. Inclusive and Exclusionary Methods

- Smith, Sumner, Hedge & Powell (2023)
 - Peabody Picture Vocabulary test
 - Four answer options with pictures
- MacDonald, Peacock, Dew, Fisher & Boydell (2022)
- Keith & Keith (2020)
- Fisher, Purcal, Blaxland, Robinson, Farrant, Kayess & Edwards (2023)
 - Environment known to participants
- Robinson, Hill, Fisher & Graham (2020) – relationship between paid support workers and people with intellectual disability
 - Mixed methods
 - Social maps, photo-research and repeated interviews

Shadowing

- Uses body language to gather insights
- Follows participants around their day
- Debrief: verbal and body language to share more information

Interviews

- Semi-structures are popular because they are flexible
- Researchers can provide support
- Inclusion is dependent on the researcher
- Perry, Waters & Buchanan (2019) – NDIS planning
 - Ten semi-structured interviews
 - 45 minutes at location chosen by participant
 - Participants wanted things written down
- If your participants keep saying they would like written material and to express themselves by writing things down, how are you ensuring their inclusion within research by conducting verbal interviews instead?

Interviews

- Meltzer, Robinson & Fisher (2020) – studied barriers in employment
 - Gave questions in EasyRead
 - Allowed people to bring a support person
 - No non-verbal participants included
- Interviews assume people can communicate verbally

Focus Groups

- Group dynamic works better for people with intellectual disability
- Group conversations helps build confidence
- Accessible environment makes inclusion possible
- Collings, Dew & Dowse (2019) – explored NDIS planning processes
 - Results to help train support people
 - EasyRead summary of themes given to participants
 - Only included people who could communicate verbally

Focus Groups

- Bridget Test
 - If verbal skills are required then Bridget will not be included
 - Accommodations can be made to include people who are non-verbal
 - Yes/No responses combined with written or observational data

Conclusion

- Gap between stated aim and execution of including people with intellectual disability in research
- History and experiences of intellectual disability usually told by other people
- Improvements are being made but people who are non-verbal are being left behind
- Methodologies need to be made more accessible to make sure all abilities are included

ANALYSED ARTICLES

		EXPLICIT MENTION OF:		
Author/s	Methods/s	Inclusion	Agency/ Empowerment	Nonverbal Inclusion
MacDonald, Peacock, Dew, Fisher & Boydell (2022)	Photovoice, semi structured interviews, group discussions	x	x	x
MacDonald, Dew, Fisher, Boydell (2023)	Photovoice	x	x	x
Perry, Waters & Buchanan (2019)	Semi-structured interviews	x	x	
Smith, Sumner, Hedge & Powell (2023)	Semi-structured interviews, observation surveys		x	x
Whitman (2017)	Interviews	x	x	
Agran, Root-Elledge, Moody, Ginn, Estrada-Reynolds (2020)	Online questionnaire		x	
Lloyd, Moni, Cuskelly & Jobling (2021)	Semi-structured interviews		x	
Meltzer, Robinson & Fisher (2020)	Semi-structured interviews	x	x	
Fisher, Purcal, Jones, Lutz, Robinson & Kayess (2021)	Semi-structured interviews, semi-structured focus group	x	x	x
Weise, Fisher, Whittle & Trollor (2018)	Focus group	x	x	x
Collings, Dew & Dowse (2019)	Focus group	x	x	
Van der Weele & Bredewold (2021)	Shadowing	x	x	x

Marston, G, Cowling, S & Bielefeld, S 2016, 'Tensions and Contradictions in Australian Social Policy Reform: Compulsory Income Management and the National Disability Insurance Scheme', *Australian Journal of Social Issues*, vol. 51, no. 4, pp. 399-417.

Grounding disability and human rights with the capabilities approach - C A Riddle in *Human Rights and Disability: Interdisciplinary Perspective* - Edited by J Gordon, J Poder, H Burckhart 2016

Human and civil models of rights: Healthy and ill disabled and access to health care - A Silvers and LP Francis in *Human Rights and Disability: Interdisciplinary Perspective* - Edited by J Gordon, J Poder, H Burckhart 2016

Vulnerability, Disability, and Agency: Exploring Structures for Inclusive Decision-Making and Participation in a Responsive State - M Mustaniemi-Laakso, H Katsui, M Heikkila, *International Journal for the Semiotics of Law*, 2022

Giving voice to vulnerable people: the value of shadowing for phenomenological research - H van der Meide, C Leget, G Olthuis, 2013, *Medicine, Health Care and Philosophy*, vol. 16, no. 4, pp. 731-737.

Human rights and persons with intellectual and developmental disabilities: An elusive but emerging paradigm - D Tarulli, D Griffiths, F Owen in *Human Rights and Disability: Interdisciplinary Perspective* - Edited by J Gordon, J Poder, H Burckhart 2016

Remarks on a disability-conscious bioethics - J Gordon in Human Rights and Disability: Interdisciplinary Perspective - Edited by J Gordon, J Poder, H Burckhart 2016

Policies to change attitudes to people with disabilities - K Fisher & C Purcal, Scandinavian Journal of Disability Research 2017, vol. 19, no. 2, pp. 161-174.

Supporting decision-making of adults with cognitive disabilities: The role of Law Reform Agencies - Recommendations, rationales and influence - S Then, T Carney, C Bigby, J Douglas, International Journal of Law and Psychiatry, 61, 2018, 64-75

Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review - EL Whittle, K R Fisher, S Reppermund, R Lenroot, J Troller, Journal of Mental Health Research in Intellectual Disabilities, 2018, vol. 11, no. 1, 69-102.

How can coproduction help to deliver culturally responsive disability support? A case study from Australia - Q Fang, KR Fisher, B Li, Health and Social Care in the community, 2021, vol. 29, 396-404.

Lives and Legacies of People with Intellectual Disability, KD Keith, HE Keith, 2020, AAIDD

Photovoice as a platform for empowerment of women with disability - D Macdonald, K Peacock, A Dew, KR Fisher, KM Boydell, SSM - Qualitative Research in Health, 2022,

Belonging and exclusion in the lives of young people with intellectual disability in small town communities - S Robinson, M Hill, KR Fisher, A Graham, *Journal of Intellectual Disabilities*, 2020, vol. 24, no. 1, 50-68.

Claiming space: photovoice, identity, inclusion and the work of disability - D Macdonald, A Dew, KR Fisher, KM Boydell, *Disability & Society*, 2023, vol. 38, no. 1, 98-126.

Factors that help people with disability to self-manage their support - KR Fisher, C Purcal, M Blaxland, S Robinson, FQ Farrant, R Kayess, Y Edwards, *Disability & Society*, 2023

On human rights and human duties: Is there a moral obligation to inclusion? - H Burckhart, B Jager in *Human Rights and Disability: Interdisciplinary Perspective* - Edited by J Gordon, J Poder, H Burckhart 2016

Perry, E., Waters, R., & Buchanan, A. (2019). Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability. *Australian Journal of Social Issues*, 54, 210-225.

Smart-speaker technology and intellectual disabilities: agency and wellbeing - E Smith, P Sumner, C Hedge & G Powell, *Disability and Rehabilitation: Assistive Technology*, 2023, 18:4, 432-442

Perceptions of Disability, Identity, Agency, Goal Attainment, and Young Adult Disability Programs, Dissertation, RK Whitman, 2017

Perceptions of Service Providers Regarding the Agency and Capacity of People with Intellectual Disability to Vote - M Agran, S Root-Elledge, E Moody, H Ginn, V Estrada-Reynolds, *Education and Training in Autism and Developmental Disabilities*, 2020, 55(1), 3-16

Lloyd, J., Moni, K., Cuskelly, M., & Jobling, A. (2021). Exploring the complexity of implementing National Disability Insurance Scheme plans for adults with intellectual disability: Parents' perspectives. *Journal of Intellectual and Developmental Disability*, 46(3), 281-290.

Barriers to finding and maintaining open employment for people with intellectual disability in Australia - A Meltzer, S Robinson, KR Fisher, *Social Policy and Administration*, 2020, vol. 54, 88-101.

KR Fisher, C Purcal, A Jones, D Lutz, S Robinson, R Kayess, *Disability and Rehabilitation*, 2021, vol. 43, no. 1, 60-68.

Shadowing or What? Experience of Shadowing Acts of Being in the Field of Education - A Knutas, *Qualitative Inquiry* 2019, vol. 25, no. 7, pp. 661-669.

What Can the Experiences of People With an Intellectual Disability Tell Us About the Desirable Attributes of a Mental Health Professional? - J Weise, KR Fisher, E Whittle, JN Trollor, 2018, *Journal of Mental Health Research in Intellectual Disabilities*, vol. 11, no. 3, 183-202.

Collings, S., Dew, A., & Dowse, L. (2019). “They need to be able to have walked in our shoes”: What people with intellectual disability say about National Disability Insurance Scheme planning. *Journal of Intellectual and Developmental Disability, 44*(1), 1-12.

Beail, N., & Williams, K. (2014). ‘Using qualitative methods in research with people who have intellectual disabilities’. *Journal of Applied Research in Intellectual Disabilities, 27*, 85–96.

Shadowing as a qualitative research method for intellectual disability research: Opportunities and challenges, S van der Weele, F Bredewold, 2021, *Journal of Intellectual & Developmental Disability*, vol 46, no, 4, pp. 340-350.